

**INTERAGENCY COORDINATING COUNCIL ON EARLY INTERVENTION
GENERAL MEETING**

May 30, 2008

MEMBERS PRESENT:

Raymond M. Peterson, M.D., MPH, Chair
Theresa Rossini, Co-Chair ICC, Chair FRSC
Jim Bellotti, Designee for the Superintendent of Public Instruction (CDE)
Arleen Downing, M.D., Chair ISH
Rick Ingraham, Designee for the Director (DDS)
Marie Kanne Poulsen, Ph.D., Chair QSDS
Beverley Morgan-Sandoz, Co-Chair QSDS
Susan Burger, Designee for (DMHC)
Hallie Morrow, M.D., Designee for the Director (CDHCS)
Suzie O'Neill, Designee for the Director (DADP)
Maureen Price, Designee for the Director (DMH)
Cheryl Treadwell, Designee for the Director (CDSS)

MEMBERS ABSENT:

Toni Gonzales
Gretchen Hester, Co-Chair ISH
Elaine Fogel Schneider, Ph.D, Chair PAC
Legislative Representative

OTHERS PRESENT:

Toni Doman, Co-Chair PAC
Linda Landry, Family Resource Centers Network of California
Debbie Sarmento, Co-Chair, FRSC
Kevin Brown, ICC Manager
Patric Widmann, ICC Staff
Stacie Reed-Byrne, ICC Coordinator
Elissa Provance, Recorder, WestEd

Refer to Attachment A for a complete list of attendees.

INTRODUCTIONS AND ANNOUNCEMENTS:

Dr. Peterson called the meeting to order at 8:50 a.m and self-introductions were made.

Dr. Peterson recognized and welcomed Susan Burger, representing DMHC, and Maureen Price, representing DMH. He also introduced three new Community

Representatives who are parents of children with special needs: Kathryn Speer from Oji and Angela Mabel White Thanyachareon from Chula Vista who will serve on the Family Resources and Supports Committee (FRSC), and Tammy DeHesa from Rialto who will participate on the Quality Services and Delivery Systems (QSDS).

Dr. Peterson announced that Governor Schwarzenegger had proclaimed April 2008 as Early Start Month in California that the 2004-05 ICC Early Start Annual Report was available, and that DDS, with WestEd collaboration, had won a Silver Award from the State Information Officer's Council for the production of the "Primary Health Care Provider's Role in Early Intervention" brochure. Toni Doman reported on the Newcomer's Orientation meeting and introduced Nora Thompson, recipient of the ICC 2008 Parent Leadership Award.

AGENDA REVIEW:

The agenda was reviewed and approved with agreement that the Parent Leadership Award presentation would follow Public Input.

APPROVAL OF FEBRUARY 2008 MINUTES:

The February 2008 minutes were approved with the revision noting the correct age of Kathy Speer's child.

EXECUTIVE COMMITTEE REPORT:

Theresa Rossini reported on the following items discussed during the Executive Committee meeting on Thursday.

1. Kevin Brown provided background information on the State's Annual Performance Report (APR) as requested by members, shared the Office of Special Education Programs' (OSEP) response to California's APR, and gave an update on focused monitoring.
2. There will be an interim Executive Committee meeting on June 25th to review the ICC's recommendations to DDS. At the September meeting, committees will meet in the morning to review edited recommendations and the Executive Committee will meet in the afternoon to address questions and approve them as an action item for the November meeting.
3. The November meeting will be a planning and celebration meeting. Executive Committee members also agreed to examine the ICC structure at the November meeting as we enter the 2009 program year in order to better address priorities and needs related to the SPP.
4. Beverley Morgan Sandoz raised the topic of Response to Intervention (RTI) expressing concern of possible delay into the Individualized Education Program and subsequently, needed services.

The Parent Leadership Work Group - In Gretchen Hester's absence Angela McGuire provided a PowerPoint presentation highlighting how the workgroup had been established, its goals, and its accomplishments. The work group was

established in November 2005 to provide the ICC with recommendations and was to end in May 2008. Initial work group goals and objectives were to:

1. Provide outreach to identify parents representing cultural diversity, various regions of the state, diversity in disability, and new/experienced parents.
2. Provide stipends for parent participation.
3. Provide child care/welcome children.
4. Develop/foster parent leadership.
5. Large-scale leadership development.

CHAIR’S REPORT:

Dr. Peterson referred to the Executive Committee meeting and provided highlights of the topics that were discussed.

ICC STAFF MANAGER’S REPORT:

Kevin Brown highlighted two handouts to the ICC, one announcing the June interim meeting with a tentative location at the Four Points Sheraton Hotel and the second handout announcing the September meeting at the Double Tree in Sacramento. Kevin also reported that Erin Paulsen has been appointed as the Supervisor for the Early Start Local Support Unit at DDS. Erin’s unit is responsible for program monitoring.

Erin introduced John Redman, formerly with Alta California Regional Center. Patric Widmann introduced Stacie Byrne-Reed, who is the new ICC Coordinator, and noted that Melissa Campos recently returned from maternity leave. One full-time position and one half-time position are still open in DDS’ Early Start Section. The Early Start Section has not been affected by the hiring freeze since they are funded by the federal grant.

FAMILY RESOURCE CENTERS NETWORK OF CALIFORNIA REPORT:

Linda Landry reported on Family Resource Centers Network of California activities. See Attachment B for details.

PUBLIC INPUT:

Julie Kingsley, Community Representative from San Marcos, reported on Excel, a SEECAP leadership training program that is sponsored by the California Department of Education. Excel consists of 3 to 3 1/2 days of interactive sessions that are very intensive and individualized.

Angela Mabel White Thanyachareon, new Community Representative from Chula Vista, is on the Board of Directors of the Infant Development Association (IDA) of San Diego and Imperial Valley. She reported on three upcoming trainings for providers and families. See pages 181-182 of the May ICC packet for details. Angela also reported that Nancy Sweet, a former ICC Community Representative, is retiring and cards are available for signing.

Theresa Rossini, ICC Co-Chair from Modesto, shared a book called “Rules” about a girl whose younger brother has autism and how she interacts with him. Both of Theresa’s sons read it at school and one son wanted to share it with his class. Theresa recommended that the book be carried in Family Resource Center libraries.

Ed Gold, ICC Community Representative from Berkeley, presented a positive experience to the ICC regarding his son who has multiple disabilities. Ed’s son recently had his Bar Mitzvah, where he was able to read prayers using a computer that synthesizes speech.

Tammy DeHesa, new ICC Community Representative from Rialto, shared how welcome she has felt at the ICC. Tammy also stated that she had attended Excel training and agreed it was an excellent opportunity for leadership development.

Toni Doman, ICC Community Representative from Crowley Lake, pointed out a DVD about autism called “JJ’s Journey”, which talks about the successes of one child and his family. Toni knows the family who put together the DVD. It is available for ordering at www.autismjourney.net or www.transitionsmovingforward.com.

Elizabeth Villanueva, a child development specialist and regional center vendor (Niños del Cielo, Inc.) shared a positive inclusion experience involving her two teenagers who are 15 and 16 and who, in 1993, went to a full inclusion preschool. Her daughter’s best friend was in a wheelchair and she helped her with activities. Now her daughter wants to become a speech therapist and her son, a physical therapist.

Kris Pilkington, ICC Community Representative from Santa Barbara, shared a story about a young man who she had worked with more than 20 years ago. His mother passed away when he was young and his grandparents raised him. Today, he lives on his own in Santa Barbara, has a DJ business, is a motivational speaker, and is diagnosed with spastic dysplasia and other challenges.

2008 PARENT LEADERSHIP AWARD:

Dr. Peterson reported that the call for Parent Leadership nominations was disseminated statewide and that the ICC was recognizing Nora Thompson, Matrix, as the recipient of the 2008 Parent Leadership Award (Refer to Attachment C for Nora’s biography). Rick Ingraham presented the award.

Rick described the nominating criteria for the award and said that Nora is the parent of four children, one of whom had special needs. She is the Executive Director of Matrix Family Resource Center and has participated on many statewide groups and task forces. Toni shared comments from those who

nominated Nora: Marin Office of Education, Blind Babies Foundation, Head Start, Golden Gate Regional Center, Deaf and Hard-of-Hearing Teachers, Public Health Nurses, and her Early Start Program Manager. Toni also read some congratulatory notes that were submitted.

Nora was presented artwork from the award-winning artist, Brenda Cruz Stewart who has special needs. Nora said she was honored and humbled by the award since she entered the field in order to help her own child, who recently passed away.

PRESENTATION – Autism Landscape

Rick Ingraham provided a PowerPoint presentation on statewide population trends in Autistic Spectrum Disorders (ASD); history of state activity; challenges, DDS' ASD Initiative; legislative interest and activity; and future challenges. See Attachment D for his power point presentation. Some of the key items discussed were:

- Challenges include a net increase of over 3000 persons with ASD annually being added to the regional center caseload, service systems that are not prepared to provide residential, behavioral, and vocational services for adults with ASD; schools struggling to serve more students with ASD; community clinicians who report being unprepared; missed opportunities for earlier diagnoses; families struggling to choose correct intervention methodologies, more appeals being filed against regional centers and schools, and use of the Internet to discover unsubstantiated “magical” cures. More and more families are carrying the burden of care since more children are living at home compared to 20 years ago. There are also tensions between publicly funded services and health plans.
- DDS is trying to improve service delivery according to best practice guidelines and guidelines recommending effective interventions. The hope is that best practices will be used as a toolkit and that the ASD Resource Project will provide consumers and families with a comprehensive collection of information on ASD.
- Capacity building is a priority and two regional center positions have been added to each regional center. DDS is also collaborating with the Senate Blue Ribbon Commission, Department of Education's Superintendent's Committee, and the DMHC ASD Workgroup; CHARGE Study (Childhood Autism Risks from Genetics and the Environment), CADDRE (Centers for Autism and Developmental Disabilities Research and Epidemiology), and other programs.
- Common recommendations across these groups include more accurate information for parents, early screening, improved professional preparation,

improved cross-cultural services; and better transition planning at age 3 and upon entering adulthood.

- Future challenges include providing services for adults; sorting through unscientific approaches; increasing the number of professionals; building data capacity; keeping current with emerging research and updating guidelines; and coordinating both locally and at the state level for funding, services, and policy.

COMMITTEE REPORTS:

Family Resources and Supports (FRSC):

Debbie Sarmento provided an overview of the committee's activities (Refer to committee minutes for details). Debbie shared that the FRSC is working on a respite paper with WestEd support and requested that position papers be included in the ICC Handbook (Note: Recommendations and position papers have routinely been included in the ICC Handbook.)

Integrated Services and Health Committee (ISH):

Arleen Downing provided an overview of the committee's activities (Refer to committee minutes for details). The Committee expressed pleasure about the newly revised "Primary Health Care Provider's Role in Early Intervention" brochure but wanted more information about dissemination.

Arleen recognized the service of Ivette Peña to the ICC and to ISH. It was suggested that the Early Start Poster be signed by ICC members and community representatives and that the poster be presented to Dr. Peña.

The Committee reviewed the Best Practice Recommendation table on pg. 103 of the May ICC packet and was unclear what the recommendations were. This will be discussed further at the next meeting. Suzanne del Sarto announced that a Community Communication toolkit to facilitate early identification, community referral and collaboration is being developed by DDS, Department of Health Care Services, American Academy of Pediatrics and others.

Since a change in ICC priorities may influence the committee structure, Arleen stated that the greatest consideration in restructuring is to have more parents on the ICC with young children who could wear several hats.

Public Awareness Committee (PAC):

Toni Doman provided an overview of the committee's activities (Refer to committee minutes for details). Toni shared that Shirley Stihler is retiring from the Monterey County Office of Education and will be resigning from the ICC after the September meeting.

Janet Canning, CDE, informed the PAC that there is an effort by California Teacher Credentialing to add an authorization for a communication specialist to the education credential.

The Committee supports an ICC presentation on RTI and supports extending an invitation to Alan Coulter to present at the November meeting.

Quality Services and Delivery Systems (QSDS):

Marie Kanne Poulsen provided an overview of the committee's activities (Refer to committee minutes for details). Marie reported that Kris Pilkington and Wendy Parise provided a report on the status of revisions being made to the ICC Recommended Personnel Model. The revisions are being prepared by a workgroup chaired by Kris Pilkington, Wendy Parise and Maurine Ballard Rosa in collaboration with a Stakeholder Workgroup. Competencies will be revised during the summer and fall and brought back to the group for review. Marie shared another initiative to revise the 2003 infant and family mental health guidelines and competencies. The two committees will work together to look at competencies for core providers.

AGENCY REPORTS:

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Department of Mental Health (DMH) – Maureen Price reported on the following activities:

Budget

Budget Balancing Reductions of General Funds total approximately \$17.4 million in the current year and 76.8 million in the budget year 08-09. Budget year reductions are calculated from workload budget levels, i.e. population, federal and court-ordered mandates, enrollment, caseload, inflation, one-time expenditures.

The following are some highlights from the Governor's May Budget Revision regarding Department of Mental Health:

- **AB 3632 (Services to Handicapped Students):** No reductions or changes to this state and federally-mandated program for either current or budget year. \$52 million in State General Fund (SGF) is identified in the budget.
- **Early Mental Health Initiative:** No reductions in the current year. A 10% reduction to this program (which provides mental health assistance to school-aged children) in the budget year, for a total reduction of \$1.6 million.

- EPSDT (Early and Periodic Screening, Diagnosis, and Treatment). The May Revision for the current year includes an increase of \$113.1 million in reimbursements due to a change from cash –based accounting to accrual-based accounting. The May Revision for the budget year includes a net increase of 24.7 million for community mental health services.
- Healthy Families Program: Current Year: Includes a decrease of 2.6 million due to a decrease in forecasted claims for the current year. Budget Year: Decrease of \$6.4 million primarily due to lower than projected HFP claims.

Mental Health Services Act

In November 2004 California voters approved Proposition 63, the Mental Health Services Act (MHSA). The Act provides a vision for transformation in the delivery of public mental health services. Specifically, the Act requires the development and implementation of client and family driven, integrated, culturally competent, and recovery/resiliency oriented services within a collaborative environment.

Prevention and Early Intervention

The Prevention and Early Intervention (PEI) Component of the MHSA covers all age groups.

Early Intervention, as defined in the PEI guidelines, can be found at www.dmh.ca\MHSA. Early Intervention strategies are directed toward individuals and families for whom a short-duration (usually less than one year), relatively low-intensity intervention is appropriate to measurably improve a mental health problem or concern very early in its manifestation, thereby avoiding the need for more extensive mental health treatment or services; or to prevent a mental health problem from getting worse. (Examples: mental health consultation/with interventions in child care environments; parent-child interaction training for children with behavioral problems; anger management guidance; and socialization programs with a mental health emphasis for home-bound older adults with signs of depression)

For individuals participating in PEI programs, the Early Intervention element:

- Addresses a condition early in its manifestation
- Is of relatively low intensity
- Is of relatively short duration (usually less than one year)
- Has the goal of supporting well-being in major life domains and avoiding the need for more extensive mental health services

- May include individual screening for confirmation of potential mental health needs

Counties have begun submitting PEI Component plans for review to the MHSA Oversight and Accountability Commission and to DMH. Plans have been received from Plumas, Mono and Monterey. These plans can be viewed at www.dmh.ca.gov/MHSOAC.

Department of Managed Health Care (DMHC) – Susan Burger reported on the following activities:

Many people are not aware that there is a HMO Help Center under the California Department of Managed Health Care. We actively advocate for the best interests of health plan enrollees. The Help Center receives and resolves enrollee complaints to ensure that enrollees receive all the necessary care to which they are entitled, including medical and mental health services. We are aware that many parents of children in the autism spectrum are having difficulties getting services they desperately need. So our office can help, we have prepared a short article that we would like you to use in your newsletters, place on bulletin boards, and on your websites.

In addition, we have brochures and guides that we can send your organizations if you have a way of circulating them. We would appreciate you placing our link www.hmohelp.ca.gov to your website if you have one, so we can help those enrollees that are having problems, or to provide other information that might be useful. We are here to help!

Department of Developmental Services (DDS) – Rick Ingraham reported on the following activities:

DDS is currently reviewing potential cost containment measures in lieu of the State's budget situation. Regarding Early Start, family cost participation will be expanded to include birth to age three. Only three services are contained under family cost participation - respite, child care, and camp. If the family meets income criteria, they will be expected to pay for 10% of the service or forgo the equivalent amount of the service. In IDEA Part C, it is discretionary for a state to serve high-risk infants. Eleven states do, one of which is California, and it will be on the table for cuts since it is discretionary. However, this action has not moved forward. DDS tries to educate new legislators as they come in showing research that \$1 spent on an infant/toddler in early intervention saves \$10-12 in services for the same infant/toddler in later special ed costs and adult services.

There is a Part B/Part C Overlapping Data Managers meeting OSEP next week in Baltimore. OSEP will also be releasing state determinations next week, of

which states can receive one of four rankings: Meets requirements, needs assistance, needs intervention, or needs significant intervention. Last year, California received needs intervention.

DDS recently (April 2008) published and posted to its website the 10th edition of its “Fact Book”. The book presents pertinent data about the individuals served by the Department, including an overview of services and trends in California.

The semi-annual Health and Wellness Forum will be in September 24-26 in San Diego, with five tracks— one focusing on early intervention and another on autism spectrum disorders. The early intervention track will consist of screening and early identification; cultural differences in parenting; feeding challenges; and assistive technology. The track on autism spectrum disorders will consist of differential diagnoses; intervention; recent research; and co-occurring medical conditions

Department of Education (CDE) - Jim Bellotti reported on the following activities:

CDE Activities For Infants and Toddlers

- On January 22, 2008, Jack O’Connell, formally released the California Preschool Learning Foundations (Volume 1). The Preschool Learning Foundations provide guidance to preschool administrators, teachers and parents on what children should know and be able to do. Preschool Field Meetings on Preschool Learning Foundations for Special Educators will be held in Sacramento on June 5, 2008. More information can be obtained by contacting phoning 916-228-2379 or through e-mail at hdavis@scoe.net.
- The *A Composite of Laws: California Special Education Programs* (30th Edition, 2008) has been published. The order form is available on the California Department of Education, Special Education Division website.
- Pamela Quiroz and Meredith Cathcart developed a presentation on Transitions. This presentation will be conducted in June at the Skillbuilders III conference. The Skillbuilder conferences are a three part series developed by the Department of Developmental Services (DDS) and West Ed for Service Providers and Regional centers throughout California.
- On June 3, 2008, the Special Education Division will host the Improving Special Education Services (ISES) stakeholder meeting. The purpose of this meeting is to bring California stakeholders to learn and discuss the update to the Part B State Performance Plan (SPP) and the Annual Performance Report (APR).

Legislative Update

- Assembly Bill 1768 (Evans) requires local education agencies, during the pendency of a hearing involving an application of a pupil for initial special education services under a preschool program who is no longer eligible for Part C services because he or she has reached age 3, to continue to provide the same services that were provided under the Part C program.
- Assembly Bill 1872 established the State Autism Spectrum Disorder Clearing house within the CDE to provide evidence-based and recommended information and practices regarding the education of pupils with autism spectrum disorders.
- There are a number of other special education bills that have been introduced this legislation session. A copy of those bills is appended to this report.

Budget Update

- The May Revision to Governor's Budget was released May 14, 2008. The revision: (1) does not provide for a cost-of-living adjustment (COLA) for schools; (2) provides a Proposition 98 General Fund increase of \$234.1 million; and (3) includes the 10 percent reduction in all state operations that was first proposed in January 2008.

Interagency Collaboration Activities

- The California Head Start-State Collaboration Office is working with the Special Education Division, WestEd consultants (Anne Kushner and Linda Brault) and Region IX Head Start on a survey for Head Start and Special Education partners to glean information on inclusion practices and problems in Head Start programs. The survey will be conducted in June and be used by an ad hoc inclusion workgroup to plan training events and products. For more information, please contact Michael Zito of the Child Development Division.
- Pamela Quiroz participated in development of the Head Start Collaborative Inclusion Survey. The CDE Collaboration Office developed the Survey to identify the degree to which policies and practices are in place and implemented to support the inclusion of young children with individualized education programs (IEPs) in Head Start. The survey was developed in conjunction with Region IX Head Start TA Network, the CDE Collaboration Office and Special Education Division. The Survey has been distributed to all Head Start programs throughout California. The outcome of the survey will be a set of recommendations for activities that will support an increase in the numbers of children with IEPs who are successfully enrolled in the California Head Start Programs.
- Pamela Quiroz participated in the SEEDS and SEECAP Conference held at the Sacramento Double tree in March. Sharon Walsh discussed transition. Pamela Quiroz attended the Early Start Personnel Model Work Group in April. The work group reviewed the draft of the proposed revision

to the ICC's recommended Early Start Personnel Model. The work group provided WestEd with several recommendations to the draft copy. It is estimated that the Quality Service Delivery Systems Committee will review all changes to the draft document at the September ICC meeting. The final version of the document will be presented to the ICC in November.

Department of Health Care Services (DHCS) - Dr. Hallie Morrow reported on the following activities:

CCS

- Handout of Numbered Letters provided
- Webpage: www.dhcs.ca.gov/services/ccs
- Pediatric Palliative Care
 - Medi-Cal waiver submitted to the Centers for Medicare and Medicaid Services. The Department anticipates the waiver will be approved and estimate an implementation date of January 2009
 - New webpage: www.dhcs.ca.gov/provgovpart/initiatives/ppc
- Branch is working with the counties to have a CCS liaison nurse on-site at tertiary hospitals to review cases and authorize services

High Risk Infant Follow-up (HRIF) restructured program

- Between July 1, 2006 and May 21, 2008, 8081 infants have been enrolled.
- New webpage: www.dhcs.ca.gov/services/ccs/Pages/HRIF.aspx

NHSP

- Expansion – 35 of the 97 non-CCS approved hospitals have been certified
- 211 hospitals currently certified
- Responses to data management service Request for Proposals have been received. Expect to issue a Notice of Intent to Award by the end of June.
- Medi-Cal continues work on a Request for Proposals to procure a vendor for the bulk purchase of hearing aids.
- New webpage: www.dhcs.ca.gov/services/nhsp

Legislation

- SB 1594 (Steinberg) – Creates minimum requirements for entities providing blood factor products for Genetically Handicapped Persons Program (GHPP) clients. In Senate Appropriations Committee

Budget

- Budget Balancing Reductions – approved by Legislature and signed by Governor
 - 10% reduction in provider reimbursement for Medi-Cal, CCS, and GHPP – effective 7/1/08
 - Several providers (pharmacy, durable medical equipment, audiology, hearing aid, and specialty physician) have threatened to discontinue

providing service to the Medi-Cal, CCS, and GHPP population if this reimbursement reduction goes into effect

- Proposed for 7/1/08
- Decrease NHSP contracts by 10% of General Fund dollars
 - Decrease General Fund money to Counties for the administration of the CCS, MTP, and CHPD programs by 10%
 - Decrease CMS Branch support budget by 10% resulting in the elimination of 23 positions
 - The last 2 Medi-Cal payments in June will be held until July
 - CCS claims received after July 1 will not be paid until a budget is signed
 - August Medi-Cal claims will be held until September
 - Restrictions to Medi-Cal eligibility being discussed
 - Premium increases for Healthy Families and the AIM program
 - MRMIB working on disenrollment regulations if caseload decreases are needed
 - GHPP has a current year deficit of \$16 million due to the increased caseload and the consequent increase in the use of blood factor products for clients with hemophilia

Department of Social Services (DSS) - Cheryl Treadwell submitted an electronic report which was read in part by Kevin Brown.

Current status of your Department's activities relevant to children birth to three.

- The Department has entered into a contract with Co-Investment Partnership and the Youth Law Center, to train social workers and foster parents in understanding the impact of making appropriate placements of infants.
- April was declared Child Abuse Prevention Month – Featured all the County Child Abuse Prevention Councils and featured Prevention Summit held to honor leadership, parents and effective programs.
- May is Foster Care Month – Various activities were held to highlight not only the needs of foster children but to honor effective programs and leaders. A Kick-Off Event was held at the Capitol. There are 84,000 children in foster care (Including probation youth).
- June 12-14, 2008 Wraparound Institute, Anaheim Marriott. Features a special Institute that focuses on Family Partnerships. Enrollment website – UC Davis Resource Center for Family Focused Practice.

Relevant Budget Update

See CDSS Website for Highlights – Proposed cuts in Welfare programs, IHHS and foster care.

Interagency collaboration activities relevant to children birth to three

- The CAPTA Summits were completed in March. Attendees (268) included participants from 18 counties, 21 regional centers, SELPAS, family resource centers and mental health partners, county offices of education; State partners from First Five, Maternal and Child Health, and the Department of Mental Health.
County teams were able to build relationship and develop work plans to put protocols and procedures into place.
- Plans are underway to make the tools and information available to other counties that did not attend the meetings and post on State website.

Screening Collaborative Workgroup meeting quarterly to establish statewide protocols for developmental screening of all children- with a focus on CAPTA mandates. Next meeting June 10, 2008. MCH has been the lead of the group.

Department of Alcohol & Drug Programs (DADP) – Suzie O'Neill reported on the following activities.

Budget

The Department of Alcohol and Drug Programs (ADP) proposed budget for Fiscal Year (FY) 2008-09 is \$662.5 million. This represents a total decrease of \$17.4 million as compared to the FY 2007-08 Budget Act Appropriation of \$679.9 million. Of the total \$662.5 million, \$606.2 million (91.5%) is for local governments and communities to provide treatment, recovery, and prevention services; and \$56.3 million (8.5%) is for State Support.

Fetal Alcohol Spectrum Disorder (FASD) Task Force

ADP's Director Zito has designated FASD as an area to be addressed and has dedicated staff to the subject area.

A letter has been signed by Director Zito of ADP and forwarded to Dr. Horton, Director of the Department of Public Health, to address manufactures to place a warning label in all at-home pregnancy kits. Dr. Horton signed the letter and the letter will be mailed the week of May 27th.

At the February 6, 2008, FASD Task Force meeting, Tony Anderson stated Assemblyman Beall was inquiring about FASD issues. Assemblyman Paul Cook briefly attended the meeting to state he was interested in helping the FASD Task Force on FASD issues.

The Task Force discussed having the alcohol industry help pay for the costs of alcohol abuse, as the tobacco industry has done.

Legislation

Assemblyman Beall has introduced AB2129 – Maternal health: alcohol and substance abuse screening and treatment. The bill addresses FASD issues and wants the Department to, "...develop, coordinate, and oversee the implementation of a model program for the universal screening, assessment, referral, and treatment of pregnant women and women of childbearing age who are suffering from drug and alcohol abuse." (This bill is quoted in part.). This bill was re-referred to Committee on Appropriations; hearing date is April 23, 2008.

Article

Good Morning America aired a program entitled, "Drinking Can Pregnant Women Drink Alcohol in Moderation? Doctors Say Lack Of Studies Make It Hard To Tell What's Safe; Women Fear Stigma". To see the response from this show, see the below article.

Drinking During Pregnancy: Is it Really Okay?

I am a member of several different list serves for clinicians, researchers and teachers of psychology and mental health topics. A hot button issue spurring a lot of discussion on one of these list serves is the group's reaction to a recent ABC News video segment (and published story on their website). This video segment depicted two women in their 30s who are 8 months pregnant with their first child. One woman has made the choice to not drink at all during her pregnancy, while the other drinks a glass of wine four or five days a week. In theory, I assume the story was supposed to present the pros and cons of drinking alcohol during pregnancy. In reality, the "take home message" of the story was that moderate drinking (of an unspecified amount) during pregnancy is okay.

This is an issue that draws an emotional reaction from many people- from pregnant women and their spouses; to parents in general; parents of children who have been affected by fetal alcohol spectrum disorders (described below); researchers/scientists, and health care professionals; and finally, "people on the street" who see a pregnant woman drinking. Clearly, the reactions may not always be based on the best available medical and scientific information, but rather, get intertwined with other emotionally charged ideas of self-sacrifice, personal freedom, and privacy issues.

Unfortunately, the ABC video segment did not provide the audience with additional research-based medical/scientific information that could help pregnant women make a more well-informed decision. Rather than presenting different viewpoints and data, the reporter interviewed only one "expert" (Dr. Moritz) during this story. This expert may be a wonderful practicing physician, but he made two statements that cloud the issue. The first statement was false, while the other was (hopefully) unintentionally misleading because it omitted crucial facts.

Problematic Point #1:

Dr. Moritz acknowledged that The American College of Obstetricians and Gynecologists and the March of Dimes **recommend zero alcohol consumption** during pregnancy. However, he went on to say that these recommendations are "very, very strict" and resulted from the fact that "there are no studies done."

This first point is problematic because we do have studies suggesting that alcohol can damage a growing fetus. It would be more accurate if Dr. Moritz had said that we don't have experiments of the double-blind placebo-controlled variety that would allow us to specify exactly how much (or how little), and when alcohol can be safely be consumed during pregnancy. Obviously, it would have taken a bit of airtime to tease out the meaning of this expanded sentence, but at least it would have been more accurate.

So, what exactly does my new longer sentence mean? A double-blind placebo-controlled experiment is a rigorously designed and tightly controlled type of study that is the gold standard in medical research. "Double-blind" means that neither the pregnant women nor the scientists collecting the data would know the level of alcohol that participants received during the study. Being "blind" in this sense is important, particularly when the doctors and women go on to rate their babies and children on scales of emotional, social, and behavioral development. We want to know whether prenatal alcohol exposure causes long term problems (described more below), so we will be examining these kids across time using parent reports, doctor reports, etc. Across time, moms and doctors may unintentionally subtly bias their ratings if they know that the child being discussed was subjected to a little or a lot of alcohol prenatally. Even subtle biases can create problems in studies that can lead to making incorrect conclusions.

"Placebo-controlled" means that among the different groups of women being studied would be one group (again, both experimenters and participants would be "blind" to this fact) who received a placebo, or non-alcoholic version of whatever substance they were using as the "treatment". This is an important component of an experiment that allows a researcher to more precisely determine whether it's truly the alcohol and not something else that's causing the effects on children. If women in the placebo group (who drink no alcohol) have children who are identical to children coming from women who drink several alcoholic beverages per week, then it's awfully hard to conclude that alcohol is causing the problems!

In addition to the double blind placebo control, a "true experiment" would have to be designed as follows: 1) the experimenters would need to find a large group of women who agreed to participate 2) the potential participant pool would need to be as identical as possible before starting the study (women at the same stage of pregnancy, similar body weights, similar history of previous alcohol use, similar diets, etc.), 3) the participants would need to be randomly selected from the pool

by a computer program (or another means) to ensure that everyone had an equal chance of being included in the study 3) selected participants would need to be randomly assigned to different study groups that would only differ with regard to the amount of alcohol they were consuming, 4) The method of giving the women alcohol would need to be tightly controlled and not be obviously different across groups (keeping participants and experimenters "blind"). In other words, it would be pretty clear what group you were in if you were guzzling three large goblets of wine while the pregnant woman next to you only had a shot glass full. Also, you couldn't simply tell the women to go home and drink one glass of wine 2 days a week. One woman's glass might be three ounces, while another woman might consume 7 ounces. All of these rigid study criteria would be designed to eliminate statistical biases that might influence the results of the study.

And that's only the beginning! As I alluded to before, in an ideal study, a participant would be followed across time as her fetus develops and grows (both in the womb and once he or she was out in the world). Because some effects of alcohol exposure are not readily apparent (see my discussion of Fetal Alcohol Spectrum Disorders below), participants' children would need to be followed into adolescence. Even then, the study would need to be repeated with other types of pregnant women (of different weights, backgrounds, etc) to figure out whether and how much other factors impact the influence of prenatal alcohol exposure on the development of the fetus and child.

I hope you can see where I am going with this...not only would this research be time consuming and difficult, but ethics boards (that review studies for potential ethical violations before allowing them to go forward) simply would not allow a researcher to proceed. Subjecting a group of pregnant women to this type of research simply to find out whether their children are harmed won't fly. The researchers proposing the study could not argue that the potential benefits of alcohol outweigh the potential risks. Obviously, alcohol is not designed to treat or cure diseases.

So, the best we can do is rely on less precise studies that are available. And, the studies we have clearly indicate that alcohol easily passes through the placenta and is a teratogen, or potentially harmful substance. In other words, alcohol can harm cell growth. A single binge at a critical period in the growth of the fetus, and repetitive bouts of drinking can cause problems.

So, I disagree with Dr. Moritz. There have been studies conducted. However, I do agree that the type of studies that would allow us to provide guidelines about the exact amount (and timing) of alcohol consumption have not. So, we can't say that drinking any amount of alcohol during pregnancy "will always" cause problems for the fetus. That is also untrue. We can say, though, that the potential risk of harming a fetus is there. We can also say that whether or not a fetus is damaged by prenatal alcohol exposure depends on several factors, including:

how a pregnant woman's body breaks down alcohol; the mother's weight, and the genetic makeup of the fetus and the mother.

Problematic Point #2:

In the ABC story, Dr. Moritz stated that in his many years of practice as an OB/GYN, he had never seen a case of Fetal Alcohol Syndrome (a collection of symptoms including abnormal facial features, growth deficiency, and central nervous system problems (e.g., impaired learning, memory, attention span, communication, vision, and/or hearing)). I assume that he was trying to reassure the public by suggesting that the risk of having a child with FAS if you drink while pregnant is relatively slim. However, I am troubled by what the viewer may have taken from this comment.

Here's the problem with this point: just because Dr. Moritz has not dealt with this medical condition doesn't mean that the risk isn't real or that it doesn't occur. Unfortunately, Dr. Moritz did not go on to explain that FAS is only one end (the severe or most serious end) of the spectrum of disorders that can result from prenatal alcohol use. The whole group of problems, called Fetal Alcohol Spectrum Disorders (FASD) can range from mild to severe and include physical defects as well as cognitive, behavioral, and emotional problems. Some of these problems may not be apparent right away (e.g., infants with some of these disorders don't look any different than other infants at birth). So, even though Dr. Moritz hasn't seen a child with FAS, he might have delivered a baby with one of the other disorders without knowing it.

Labels used to diagnose the range of Fetal Alcohol Spectrum Disorders include FAS; Fetal Alcohol Effects (FAE); Alcohol-related Neuro-developmental Disorder (ARND); and Alcohol-related Birth Defects (ARBD). The label FAE was commonly used in the past to describe a person with behavioral and cognitive problems who didn't have the physical characteristics to warrant a full-blown FAS diagnosis. This FAE diagnosis was eventually expanded and replaced by the labels ARND and ARBD, again keeping the idea that problems exist, but do not fit all of the criteria for FAS. ARND is used to describe people who have behavioral or cognitive problems, or a combination of (e.g., learning difficulties, poor school performance and/or poor impulse control) resulting from prenatal alcohol exposure. People with ARBD have problems with the heart, kidneys, or bones; hearing loss; or a combination of these. According to the American Institute of Medicine (IOM), 0.6 to three babies born per 1,000 have FAS. The rates of less severe Fetal Alcohol Spectrum Disorders are much higher; ARND occurs in approximately 9 babies per every 1,000 live births.

Again, the research does not suggest that every woman who drinks during pregnancy will go on to have a baby with a Fetal Alcohol Spectrum Disorder. Most won't. However, there is no fail proof way to predict whether a person is one of the mothers who will drink while pregnant and have a child with FAS, ARND,

or ARBD. The only fail proof way to prevent this event is to avoid drinking during pregnancy. That's the reasoning behind the American College of Obstetricians and Gynecologists and the March of Dimes' recommendations and also the reason why this information should have been included in the ABC story.

OTHER BUSINESS:

No other business.

ADJOURNMENT:

Dr. Peterson adjourned the meeting at 1:15 p.m.

ATTACHMENT A
STAFF AND OTHERS ATTENDING ICC GENERAL MEETING
May 30, 2008

COMMUNITY REPRESENTATIVES

Bev Ching
Terry Colborn
Kathleen Colvin
Wanda Davis
Tammy DeHesa
Toni Doman
Edward Gold
Nenita Herrera-Sioco
Julie Kingsley
Linda Landry
Dwight Lee
Al Millan
Shane Nurnberg
Lois Pastore
Kristine Pilkington
Debbie Sarmento
Kathryn Speer
Angela Thanyachareon
Sherry Torok

GUESTS

Catherine Mikitka
Susan Miller
Anne Nurnberg
John Redman
Nora Thompson
Gabriel Villaneuva
Elizabeth Villaneuva

DEPARTMENT LIAISONS

Suzanne Del Sarto
Michelle Donahue
Michael Miguelgorry
Erin Paulsen
Pamela Quiroz

STAFF

Peter Guerrero
Angela McGuire
Stephanie Myers
Kay Ryan